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Predicting psychological distress of informal carers of individuals with major depression or bipolar disorder

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ABSTRACT

Caring for someone with a mental illness is associated with high levels of burden and psychological distress. Understanding these factors could be important to prevent the development of physical and mental health problems in carers. The purpose of the present study was to determine the contribution of coping styles and social support in predicting the psychological distress reported by informal carers (IC) of individuals with major depression or bipolar disorder. IC ($n = 72$) of adults with a diagnosed depressive illness were recruited from mental health organizations within the community setting. Carers completed the General Health Questionnaire, Brief COPE, and Social Support Questionnaire. Multiple linear regression analysis revealed that 63% of the variance in psychological distress could be accounted for by adaptive and maladaptive coping styles and perceived quantity and satisfaction with social support. Satisfaction with social support ($\beta = -0.508$, $P < 0.001$) and maladaptive coping ($\beta = 0.369$; $P < 0.001$) were significant predictors of psychological distress. These findings suggest that interventions should consider coping styles, specifically

the interaction between maladaptive behaviours and enhancement of quality of support, to assist carers to manage psychological distress, especially earlier in the caring role.

KEY WORDS: coping behaviour, carer, depression, social support.

INTRODUCTION

Depression is a leading contributor to the global burden of disease (Mey et al., 2014), affecting approximately 350 million individuals across the world (WHO, 2016). Depression is a mood disorder that exists as two distinct affective disorders, unipolar depression and bipolar depression, which express similarities in terms of their low mood states and common treatment strategies (Rastelli et al., 2013; Rogers & Agius, 2012). These mood disorders greatly contribute to the medical and financial strain placed on the National Health Service (McCrone et al., 2008; Simon, 2003). They have a negative impact not only on the individual but also on partners, friends, and family members involved in their care (Crowe & Lyness, 2013; Grover et al., 2012; Johnson, 2000; Stjernswärd & Östman, 2008). Individuals who provide this care voluntarily, regularly, and outside of the umbrella of primary care are considered 'informal carers' (IC) (Goodwin & Happell, 2007; Lawn & McMahon, 2014). Being an IC of someone with mental illness is associated with high levels of burden (Chambers et al., 2001; Grover et al., 2012; Stjernswärd & Östman, 2008) and psychological distress (Crombie et al., 2007; Holmes & Deb, 2003; Östman & Hansson, 2004; Shah et al., 2010). Researchers have argued that caring for individuals with depressive mood disorders carries significantly greater burden and distress in comparison to various other physical illnesses (Ogilvie et al., 2005). This could be due to a complexity of such conditions as a result of their varied, intense, and intangible emotions, states which are invisible to the human eye (Molyneaux et al., 2011) that could result in disagreements between carers and medical professionals. The variability of mood disorders over time means carers are often forced to adapt their role without guidance or advice (Chambers et al., 2001; Rosenwax et al., 2014; Schulze & Rossler, 2005; Winefield, 2000), and experience emotional and physical exhaustion (Chambers et al., 2001; Jardim & Pakenham, 2010), frustration, resentment, and anger (Spangenberg & Theron, 1999; Weimand et al., 2013), and a moral obligation to provide constant support (Grover et al., 2012; Östman et al., 2005; Weimand et al., 2013). Evidence shows IC to be at high risk of developing depression (Wittmund et al., 2002; Song & Singer, 2006), although studies suggest coping style and social support to be important mediators in their well-being.

Coping is a complex, multidimensional process that involves managing cognitive and behavioural process to meet the internal and external demands of stressful situations (Folkman & Moskowitz, 2004). IC are routinely forced to cope with stressful, challenging, and unpredictable situations (Mackay & Pakenham, 2011; Weimand et al., 2013), and must deal with these situations while regulating their own emotions (Folkman et al., 1986). This greatly impacts their perceived capability to meet the demands of the caring situation (Carter, 2002). Coping styles can generally be classified to be maladaptive or adaptive (Carver; 1997; Moore et al., 2011; Thompson et al., 2010). Adaptive coping styles refer to those that are constructive and increase an individual's ability to deal with the demands of a stressful situation, while maladaptive coping refers to negative and dysfunctional methods that increase stress and fail to improve an individual's ability to manage the demands of the situation (Lazarus, 1999; Zeidner & Endler, 1996). Adaptive coping is more likely to result in positive outcomes and enhance functioning; for example, active coping, positive reframing, planning, humour, acceptance, religion, and the use of emotional and instrumental support (Carver, 1997; Carver et al., 1989). Conversely, while offering temporary relief to the stressor, maladaptive coping typically decreases functioning; for example, wishful thinking, emotional withdrawal, avoidance and substance abuse use.

The coping style employed is strongly influenced by how the individual appraises the situation (Lazarus & Folkman, 1984). Vasudeva et al. (2013) observed more maladaptive coping styles in IC of patients with schizophrenia and bipolar disorder when the burden of caregiving was reportedly greater. Mackay and Pakenham (2011) found carers who tended to use maladaptive coping styles had poorer general health and experienced greater distress than those who use more adaptive coping styles. This suggests that adaptive coping styles can assist to alleviate psychological distress faced by carers in a constructive manner, while maladaptive styles are problematic (Alpert, 2014; Kartalova-O'Doherty & Doherty, 2008).

Social support can act as a form of adaptive coping (Rees, 2007), and theoretically takes four distinct forms: informational, tangible, esteem, and emotional support (Rees & Hardy, 2000). For example, seeking social support, including one or more of these forms, is considered an adaptive form of coping (Saunders, 2003; Song & Singer, 2006; Thoits, 1986). Many IC report insufficient support and are unsure of how to obtain more (Douma et al., 2006), with lower levels being associated with maladaptive coping styles (Coomber & King, 2012) and high levels of psychological distress (Wijndaele et al., 2007). Enhancing perceptions of social support has proved effective in ameliorating the burden faced by carers in the context of caring for an individual with an eating disorder (Coomber & King, 2012;

Raenker et al., 2013), and therefore, provides a strong case for IC of individuals with depressive illnesses.

The caring literature has previously focussed on the IC role of patients with cancer (Thomas et al., 2002), dementia (Gilliam & Steffen, 2006), Alzheimer's disease (Cooper et al., 2008), Parkinson's disease (McLaughlin et al., 2011) stroke survivors (Greenwood et al., 2009; McGurk et al., 2011) and in a broad spectrum of mental illnesses (Kartalova-O'Doherty & Doherty, 2008; Mackay & Pakenham, 2011). Although mental illnesses have similarities, every mental illness is different and will occur along a continuum of severity. Therefore, caution must be taken when generalizing coping styles and social support of carers with different conditions (Peterson, 2009). To the best of our knowledge, no studies have attempted to examine the psychological distress of IC of individuals with depressive illnesses. Specifically, a lack of research exists examining the experiences of IC within voluntary third-sector organizations. These are non-governmental, non-for-profit organizations consisting of charity, voluntary, and community alliances. Understanding how best to support these carers is vital in assisting mental health practitioners in order to prevent the development of physical and mental health problems, as they provide fundamental support essential in improving the well-being and the treatment and recovery of the affected individual (Kartalova-O'Doherty & Doherty, 2008; Winefield, 2000). The consideration of how the duration of care influences carer psychological distress has also been somewhat overlooked in previous studies. Consequently, the purpose of the present study was to determine the contributions of coping styles and social support to the psychological distress reported by IC of individuals, specifically with major depression or bipolar disorder, recruited from voluntary third-sector organizations. It was hypothesized that carer psychological distress was linked to predominantly maladaptive coping styles being used, in combination with lower levels of satisfaction with the support they are receiving.

METHOD

Participants

A quantitative, cross-sectional design was adopted to assess the psychological distress, coping styles, and social support of IC. A total of 72 IC ($F = 51$) of adults with a depressive illness were recruited from third-sector mental health organizations throughout England and Wales, such as Depression Alliance and Rethink Mental Illness. These carers do not have access to coping and social support services as they would in a clinical settings within England and Wales, where support services are embedded within patient treatment plans.

Inclusion criteria were: (i) carer of a person with a diagnosed depressive illness (major depression $n = 53$, bipolar disorder $n = 19$); (ii) well-established caring role; minimum of 1 year in role, through familial tie and/or cohabitation; and (iii) aged 18 years or over. The majority of carers were over the age of 40 years (61%), and 74% currently lived with the person they cared for. Participants failing to meet the inclusion requirements were excluded from analysis (Table 1).

Instrumentation

A questionnaire was chosen to gain knowledge and understanding, while avoiding sensitive conversation topics so respondent anonymity was maintained. The questionnaire administered obtained descriptive information, including age, sex, and duration of caring role. The details obtained were limited to those required to confirm that the inclusion criteria were met and ensuring participant anonymity, as required by the university ethics committee. The General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988) was used to identify poorer health and perceived psychological distress. Those reporting a score of >15 indicated that the participant experienced some psychological distress, and a core >20 indicated severe problems and psychological distress (Goldberg & Williams, 1988). Coping styles were measured using the Brief COPE (Carver, 1997), a 28-item questionnaire addressing adaptive (problem-focussed) or maladaptive (dysfunctional) forms of coping, with respondents rating each item according to those they use. The Social Support Questionnaire-6 (SSQ6) (Sarason et al., 1987) assesses an individual's perception of the quantity of social support (QSS) and satisfaction with social support (SSS) they receive. The shortest versions of these validated questionnaires were used in order to reduce participant burden and enhance response rates. Cronbach's alphas for the questionnaires and subscales in the current study were 0.93 (GHQ-12), 0.83 (Brief COPE, adaptive subscale), 0.85 (Brief COPE, maladaptive subscale), 0.86 (SSQ6, QSS), and 0.98 (SSQ6, SSS), respectively, ranging from acceptable to high (Nunnally, 1978).

Procedure

Following ethical approval from the university ethics committee, mental health organizations ($n = 12$) were contacted. The procedures used are shown in Figure 1. The proposed study was put forward to the organizations' executives, where suitability to their service users was considered, relevant subgroups were contacted, and information regarding the proposed research was disclosed. To ensure data protection and anonymity, as required by the university ethics committee, the organizations were the principle controllers; they had access to the populations sampled in terms of questionnaire distribution and collection. All service

users of these organizations were free to engage or not engage at their own discretion (Gillham, 2008). Response rates varied considerably across organizations; however, due to anonymity requirements, the actual numbers of individuals per organization was unknown. All participants were provided with study information sheets, and signed consent forms (Fig. 1).

Data analysis

Statistical analysis was conducted using SPSS version 20 (SPSS, Chicago, IL, USA). Distributions for all scales, except SSS (skewness = -0.992, kurtosis = -0.372), were acceptable. Transformation of this variable yielded similar outcomes, and so the use of the original variable was deemed appropriate due to issues with transformed data (Tabachnick & Fidell, 2013). The tolerance value and the variance inflation factor (VIF) showed no issues of multicollinearity (tolerance >0.10, VIF <10), and a linear relationship was evident. A review of the Mahalanobis distances revealed no outliers above the critical value, as specified by Tabachnick and Fidell, (2013). While casewise diagnostics revealed one case to be below the standard residual value of -3.0 (-3.165), the Cook's distance was below 1.0 (0.82), indicating little impact on the overall regression. Correlations between psychological distress, duration of carer role, and sufferers' age were performed. Multiple linear regression analysis identified the variables that contributed to the level of psychological distress of carers. Variables were deemed significant if they $P < 0.05$ (Pallant, 2008). Partial correlations controlling for duration of support were also conducted.

RESULTS

Descriptive statistics of each of the independent and predictor variables are presented in Table 1. While some variables achieved midpoint mean values on the scales, maladaptive coping styles tended towards the lower end of the scale, and SSS tended towards the upper limit. The latter was also higher than the QSS, although the distributions were similar.

Results of the regression analysis are presented in Table 2. The overall model revealed that 63% of the variance in psychological distress was accounted for by the coping and social support variables (adjusted $R^2 = 0.63$, $F(4,67) = 30.87$, $P < 0.001$). SSS was the strongest contributor to the model ($\beta = -0.508$), being inversely related and accounting for 25% of the total variance in psychological distress. Maladaptive coping styles were positively related to psychological distress, accounting for 14% of the total variance. The significant beta value for SSS indicated that for every one-point decrease in SSS, there was a 0.5 increase in psychological distress. Conversely, for every one-point increase in maladaptive coping, there

was a 0.37 increase in psychological distress. Adaptive coping styles and QSS failed to make a significant contribution to the model.

To test for the effect of duration of carer role, a Pearson correlation was performed with psychological distress, which revealed a significant negative relationship ($r = -0.25$, $P < 0.05$). The analysis, using standard multiple linear regression, was repeated to introduce and control for this 'unexpected' outcome, and revealed no substantive change in the overall model or the principle predictors: maladaptive coping styles and SSS.

DISCUSSION

The purpose of the present study was to determine the contribution of coping styles and social support in predicting the psychological distress reported by IC of individuals with major depression or bipolar disorder obtained through third-sector voluntary organizations. Importantly, consideration of the duration of caring role was made. In line with previous work (Crombie et al., 2007; Holmes & Deb, 2003; Östman & Hansson, 2004), caring for someone with a mental illness was associated with a tendency for higher levels of psychological distress, evidenced by 46% of the sample meeting the criteria of either psychological distress (scores between 15 and 20, 23%) or severe problems and psychological distress (scores >20, 23%). This is a greater proportion than would be expected in a general population sample, where psychological distress is thought to affect between 5% and 27% of adults (Drapeau et al., 2012), and mental illness affects approximately 25% of adults each year (Mental Health Foundation, 2016). It was noted that 74% of this sample resided with the person they cared for, and this could explain the higher levels of psychological distress observed. Increased respite care could act as a buffer for IC who reside with the person they support (Jardim & Pakenham, 2010), although this was not explored in the current study.

Maladaptive coping styles

Results of the regression analysis revealed maladaptive coping styles to be a significant predictor of increased psychological distress, which is in agreement with the findings of other published studies (Coomber & King, 2012; Kartalova-O'Doherty & Doherty, 2008; Mackay & Pakenham, 2011). Mackay and Pakenham (2011) found that IC ($n = 87$) of individuals with non-specific mental illnesses, who relied on predominantly maladaptive coping styles, had poorer general health and experienced greater psychological distress. Maladaptive coping has also been found to be associated with higher levels of psychological distress in IC of those with an eating disorder (Coomber & King, 2012). Caring is based on the individual's perceived competency to meet the demands of the situation (Carter, 2002;

Trouillet et al., 2011), and the coping style employed is influenced to a certain extent by the carer's ability to deal with the problem and regulate their emotions (Lazarus & Folkman, 1984). Lazarus (1999) acknowledged that coping is likely to be highly ineffective in situations of high stress, and so carers' use of maladaptive coping styles could be a combination of the challenging and highly-stressful caring role, and the perception that they were unable to meet the demands of their caring situation (Mackay & Pakenham, 2011; Weimand et al., 2013), while also seeking a form of short-term relief. The significant contribution of maladaptive coping styles to increased carer psychological distress could be due to carers having entered into their caring role unprepared (Mackay & Pakenham, 2011), and so have to 'get on with it' and learn to cope through trial and error methods as situations arise (Chambers et al., 2001; Cree, 2003; Kartalova-O'Doherty & Doherty, 2008). However, the question of cause and effect, specifically whether the psychological distress triggers maladaptive coping or the latter increases subsequent distress, remains unclear from the data, and would require consideration through longitudinal studies.

Adaptive coping styles

In contrast, and in line with previous research (Pakenham et al., 2007; Song & Singer, 2006), adaptive coping styles were not related to reduced carer psychological distress. Song and Singer (2006) observed that adaptive coping styles (in particular, approach coping) failed to significantly predict a reduction in depressive symptoms of family carers ($n = 351$). Furthermore, Pakenham *et al.* (2007) considered how adaptive coping styles, such as acceptance, problem solving, and seeking social support, could predict global distress, where all adaptive methods failed to be significant contributors. According to Folkman and Mosowitz (2004), a carer's use of adaptive coping styles will not necessarily lead to a permanent resolution of the problem, which could account for the disconnect between adaptive coping styles and psychological distress in the current study.

Social support

Although QSS and SSS were both negatively associated with psychological distress, the regression analysis revealed only the latter to be a significant predictor. SSS was the strongest significant predictor in the model of the psychological distress faced by IC supporting an individual with a depressive illness. The findings of the present study are consistent with those of other authors; for example, Wijndaele *et al.* (2007) observed overall social support to be negatively associated with perceived levels of distress. Greater SSS has also been associated with significantly lower levels of distress in IC ($n = 101$) of adults with mental illness (Mackay & Pakenham, 2011). This might be due to the strong stress-buffering

effects social support has as a valuable coping resource (Rees, 2007; Song & Singer, 2006). Furthermore, Pakenham *et al.* (2007) found that a large social support network (QSS) failed to significantly predict global distress in young carers. The lack of significance may be explained as carers who receive support from various support groups are also reported to have smaller social networks (Mannion *et al.*, 1996), indicating they possess few local contacts. The reasons for smaller local support groups include circumstances that limit free time and the availability of other similar IC, due to a trend towards becoming reclusive and friends becoming dismissive or unavailable (Chambers *et al.*, 2001; Stjernswärd & Östman, 2008).

When the level of SSS, as perceived by the recipient, is high, this could protect against raised psychological distress, and thus, they would not necessarily look to seek additional support. Those with low SSS might seek to enhance this, but personal and environmental constraints could limit opportunities. In addition, the establishment of satisfying sources of support might require a longer timeframe commitment. However, these findings are in contrast to Song and Singer's (2006) where no relationship was found between social support and carers' depressive symptoms, and also Coomber and King's (2012), where SSS did not contribute to the prediction of psychological distress of IC of individuals with eating disorders. Various reasons could exist for these differences: illness of patient, age of sample, the recruitment strategy and/or the current sample being limited to the voluntary third sector. . Previous studies have included individuals from numerous environments, such as educational institutes and clinical settings, where various forms of social support could be more accessible and plentiful. Social support was also measured using three subscales: instrumental, emotional, and satisfaction with social support, over a longer, 1-year timeframe (Song & Singer 2006). Future studies that provide an in-depth understanding of this dynamic, as well as the distinct forms of social support, as proposed by Rees and Hardy (2000) (informational, tangible, esteem, and emotional), are required.

Duration of care

Duration of the caring role showed a weak, negative relationship with psychological distress, suggesting lower levels in those who have been in the role for longer periods. In contrast, Hirst (2005) reported a positive relationship between duration of care and higher levels of distress, although the nature of the sample, accuracy in recall, and response bias cannot be excluded as possible explanations for this difference. When the duration of the caring role was introduced into the model, little change was observed in the importance of SSS and maladaptive coping in their predictive effect on psychological distress. This

indicated that efforts to achieve enhanced SSS and recognition of maladaptive coping strategies could be useful to all carers, irrespective of the length of time they have been in the role.

Strengths and limitations

The main strength of the present study was that it has explored psychological distress, coping and social support in a group of individuals who play a vital role in the support and care of people with depression, recruited exclusively through the voluntary sector. To the best of our knowledge, no previous studies assessing IC distress have recruited participants from third-sector voluntary organizations, incorporating a wide range of mental health charities across England and Wales. The inclusion of those carers, from what could be considered an 'invisible population' (Lawn & McMahon, 2014), has allowed insight into the psychological distress they faced away from a clinical inpatient environment, as in previous research, making our study unique. Employing recruitment methods solely from a community setting, although more arduous, could also be regarded as more generalizable to the wider carer community. Finally, a specific group of carers has been considered, as opposed to generalizing mental illness with the inclusion of multiple conditions. This is particularly important, as mental illness varies in nature and severity (Peterson, 2009).

Although the present study has a number of strengths, it also has limitations. Engagement of those carers experiencing high levels of psychological distress might be low, as suggested by Lazarus (1999), and this possible effect would need to be explored. The use of mental health organizations to recruit might have excluded those individuals more socially isolated, while including carers receiving some form of related social support. To control for the variety of organizational social support, it could be useful to consider the use of 'within mental health organization' studies, where carers have access to similar social support networks. Additional information on the carer's level of support from, and engagement with, voluntary organizations might be useful for understanding this factor. Likewise, the present study's reliance on third-sector organizations with varied recruitment procedures made a prior response rate difficult to predetermine, and makes replication of this study more difficult. Finally, as the sample in the present study is diverse in terms of participants' age range and the length of time cared for, future research is needed using a larger sample to compensate for the breadth of age groups and length of time cared for.

Implications for practice

As carers are routinely forced to cope with stressful, challenging, and unpredictable situations (Mackay & Pakenham, 2011), a key outcome for clinical practice would be the

development of carer-focussed interventions that assist carers to manage their perceptions of psychological distress and those that encourage them to adopt a variety of coping styles (Tennakoon et al., 2000) that they can adapt to their unique carer role (Folkman & Moskowitz, 2004). Further consideration by health-care professionals of the coping profile at a more individual level is important to improve carer health and well-being (Campos et al., 2014). Facilitation of carer support groups would provide carers the opportunity to share their coping experiences and learn from one another through peer support (Campos et al., 2014; Stjernswärd & Östman, 2008). It is important that health practitioners make carers feel supported, as by doing so, carers are more likely to trust the decisions made (Ayra, 2014). Confiding in and sharing experiences with other carers with similar caregiving experiences are invaluable forms of quality social support (Chambers et al., 2001; Weimand et al., 2013), offering carers an alternative understanding of how to cope with the demands of their caring role (Chen & Greenberg, 2004). In addition, QSS has the potential to result in more successful patient recovery (Chambers et al., 2001; Moore et al., 2011), lessening demands on health-care systems (Hill et al., 2007; Van Exel et al., 2007). It will also assist in preventing carers themselves from falling ill (Stjernswärd & Östman, 2008). In light of this sample, the data suggest that interventions should be applied soon after the initiation of the caring role and that they continue in the long term through various avenues. These might include education; small, local, IC groups; referral to voluntary sector organizations; and clinically-led carer support groups, with an emphasis on providing quality support, as judged by the carer.

Conclusion

In summary, SSS and maladaptive coping styles interact with the level of psychological distress experienced by carers of depressed individuals. Strategies to enhance SSS would seem logical to reduce distress, although changing maladaptive coping styles might be more complicated because of its cause-and-effect dynamic with psychological distress, and because maladaptive coping styles for some individuals might prove 'adaptive' for others. The cross-sectional design of the present study suggests that the interaction between these variables plays an important role in carers' mental well-being, and this understanding needs to be extended in a variety of ways. Future research should implement and test the effect of coping style modification and social support strategies on the psychological well-being of IC. Further development of this work to understand the individual's experiences over time would be an important step in the understanding of carers' psychological distress, social support, and use of maladaptive and adaptive coping styles.

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TABLE 1: *Descriptive statistics of carer measures, results are shown as mean (SD) and ranges*

Variable	Mean (SD)	Range
Age (years)	43 (17.4)	18–80
Cohabitation duration (years)	18.9 (13.9)	1–53
Support duration (years)	7.5 (7.9)	1–36
Psychological distress (GHQ-12)	16.4 (7.2)	0–33
Adaptive coping (Brief COPE)	40.1 (8.1)	24–62
Maladaptive coping (Brief COPE)	24.8 (7.4)	13–44
Quantity of social support (SSQ-6)	2.4 (1.5)	0–6
Social support satisfaction (SSQ-6)	4.5 (1.5)	1–6

GHQ-12, General Health Questionnaire; SD, standard deviation; SSQ-6, Social Support Questionnaire-6.

TABLE 2: *Standard multiple regression analysis for predictor variables on psychological distress*

Model	Unstandardized		Standardised	<i>t</i>	<i>P</i> -value
	Coefficients		Coefficients		
	B	SE	β		
(Constant)	20.167	3.716		5.43	<0.001
Adaptive coping	−0.033	0.079	−0.037	−0.415	0.679
Maladaptive coping	0.358	0.081	0.369	4.423	<0.001
Quantity of social support	−0.301	0.521	−0.057	−0.578	0.565
Social support satisfaction	−2.381	0.558	−0.508	−4.266	<0.001

$F(4,67) = 30.87$, $P < 0.001$. SE, standard error of mean.

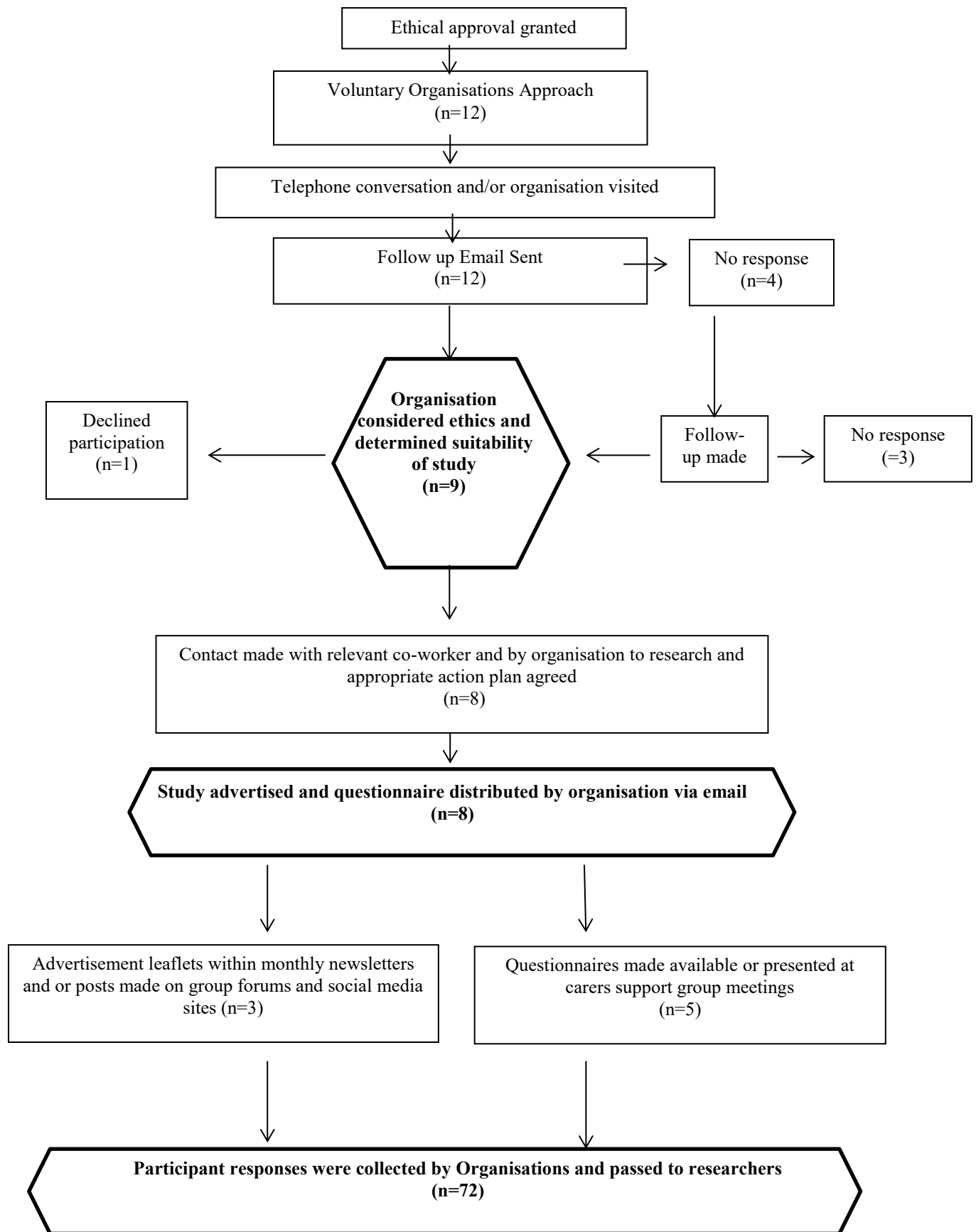


FIG. 1: Process of recruitment of non-for-profit organisations and participants